



Parents 4 Change  
Fifth Conference

Wednesday 13<sup>th</sup> October 2010

Riverside Stadium,  
Middlesbrough

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## **Introduction**

Ruth Johnson, Parent Steering Group Member

Ruth introduced herself as a member of the Parents 4 Change parent led steering group and welcomed everyone to the fifth conference.

The Parents 4 Change group works in partnership with the local authority to improve services for disabled children, young adults and their families throughout Middlesbrough.

They believe that disabled children and young adults should be able to access services and activities without discrimination or exclusion. The group are striving to make a difference for their children and for future generations.

Ruth introduced the professionals who were in attendance at the conference and who were available throughout the day for questions and for sharing information.

## **Update on Parents 4 Change**

Mary Harland, Parent Steering Group Member

### **What has been achieved?**

- 4 conferences have been held prior to this one
- Focus Groups have been set up on the priority areas identified by parent/carers at these conferences
- Been involved in setting up the Key Working Pilot
- Worked on Short Break provision
- Helped to develop a Text Alert service
- Set up a website which is now being updated regularly  
**[www.parents4change.co.uk](http://www.parents4change.co.uk)**

### **Short Breaks**

- Work done on criteria for access to enable more families to enjoy a short break
- Days out organised including Flamingoland
- Individualised Budgets Pilot Scheme operated

### **Transitions**

- Worked with Transitions team
- Booklet being developed
- Draft copies to be available at conference

## **Sport and Leisure**

- Looked at different activities on offer
- Set up the new youth club for disabled children at Kader Youth & Community Centre
- Set up a girls group (an idea from families from the Asian community who asked for a single sex activity group)

## **We need to keep it going**

- Work must be allowed to continue
- Funding needed beyond April 2011
- Need for greater support from parents and carers so everyone is encouraged to sign up and get involved

## **National Network of Parent Carer Forums**

Sheila Tunney, Parent Steering Group Member

Kathy Rist, Regional Manager Contact a Family North East & Regional Parent Participation Adviser, Together for Disabled Children

Sheila spoke about the greater strength of voice when parents come together, something that is happening not only with Parents 4 Change in Middlesbrough, but with other parent forums linking together regionally and now nationally.

Parent members from the Parents 4 Change steering group have attended regional events to share information with other parents from across the North East.

At the last event, those in attendance were asked to consider standing as the North East representative for the newly formed National Network of Parent Carer Forums (NNPCF). Those that wanted to stand spoke at the event and everyone in attendance then voted.

Johanna Smith from North Tyneside was voted to be the North East representative (with Marsha Dolan from County Durham as deputy).

Sheila stressed the importance of supporting Johanna in her role. The NNPCF have already met with Sarah Teather, Minister with responsibility for Children with Disabilities and Special Needs, who is supportive of the process.

The tagline for NNPCF is **Our Strength is in our Shared Experience** and Sheila therefore encouraged more parents in Middlesbrough to get involved to help to strengthen parents' voices even further.

Kathy Rist stressed how significant it was that parents are members of this national taskforce from across the whole country. The NNPCF has the ear of the Government who are now looking at what has been achieved through Aiming High and where and how money has been spent.

Parent Participation and involvement is seen as the most successful part of Aiming High and local parent involvement has had a national impact through parent power and influence.

Kathy echoed Sheila in encouraging Middlesbrough parents to continue their efforts and further develop the whole Parents 4 Change process.

## **Update from the Mayor of Middlesbrough**

### **Ray Mallon**

Ray has been made aware of the Parents 4 Change process through speaking at a previous conference. He was also recently invited to attend a parent steering group meeting, an invitation he was happy to accept.

The key points made by Ray during his speech were:

- Sees Parents 4 Change as a group that is lobbying for change
- The group supports his belief that everyone in Middlesbrough has a voice and a stake in what happens in their future
- The principles of the Parents 4 Change process support the wider inclusion agenda that Ray has been working towards during his eight years as Middlesbrough's elected mayor. In effect to ensure that **everyone** in Middlesbrough has a voice and a stake in what happens in the future.
- Some recent personal experiences (of being temporarily disabled), along with the views of the Parents 4 Change group have raised his own awareness around the issues faced by disabled people and their carers
- The Council is facing a very difficult financial situation and there will be pressure on budgets. Ray will do all he can to limit the effect on services for children with disabilities.
- Committed to supporting the Parents 4 Change process and will do his best to ensure the sustainability of the group beyond March 2011 when the Aiming High Participation grant will come to an end
- Would like the group to regularly contact him with achievable tasks that they would like him to look into
- Wanted to congratulate all the parents involved in the process for their commitment and for the many achievements the group have facilitated already

## Short Breaks

Kerrie Morrison, Parent Steering Group Member

### What will happen when the Aiming High money ends?

Background

- In July 2006, a Parliamentary Hearings Report concerning children with disabilities and their families said that:

**“The lack of short breaks was the biggest single cause of unhappiness with service provision”**

- In May 2007, it was announced that there would be, as part of the “Aiming High” programme, a specific grant to change the provision of short breaks.

A Visioning Day was held in Middlesbrough in December 2007 which brought together 80 parents/carers and staff to talk about short breaks provision.

From this day, parent/carers produced the following visioning statement:

Middlesbrough will have a short break service where:

**“Disabled children, young people and their families are involved in developing a range of flexible, and easily accessible, high quality short break services and activities, enabling them to reach their full potential and maintain family stability - make it so!!!!”**

Parents 4 Change has worked with staff in the Short Breaks Focus Group, and in consultation events such as the “Big Event” for children and young people, to develop a range of short break services in Middlesbrough.

### Outings and Activities

Short breaks used to mean children with disabilities having time away from their families.

Our message was that, while this is very valuable, many families also want a short break to include support to help do things as a family.

Families wanted:

- **“activities to include all the family”**
- **“a break for the whole family – especially the siblings”**

One parent said:

- **“I want to keep my child in the family environment but to be able to access things that any other family can access”.**

Parents 4 Change has helped plan activities and events including:

- Visits to Pantomimes and Disney at Tele-West Arena,
- Trips to Lightwater Valley, Flamingoland, Eureka, York Railway Museum, Beamish, Sea Life Centre
- Activity Days including Stewart’s Park, Nature’s World, Ormesby Sports Centre and North Ormesby Community Centre

Parents have said:

**“My child loves his short breaks as it helps him to meet and mix with children who do not judge him or make fun of him. It is so important for him to try and have a normal life, which he would not get without these trips.”**

**“It is great for the children but also for the carer. I am a carer for 3 (2 are on night time machines). Day trips are great.”**

**“The family trips out has given families the opportunity for them to enjoy themselves as a family unit and strengthen family ties as a result, also the opportunity to mix with other families in similar situations”**

**“Been to places that I couldn’t afford to go to myself as I have not got transport. And my children really appreciate it.”**

### **Play schemes in school holidays**

Families find that school holidays, particularly the Summer holiday, are very challenging.

Parents at the Parents 4 Change Conference in November 2008 said they wanted: **“activities at weekends and school holidays”**

Some children have been given extra support so that they can access mainstream Play schemes

Funding has been given to services, such as The Main Project and Great Expectations, to provide support during the school holidays. Parents 4 Change members chose which organisations should receive funding.

A new Play Scheme (The Fun Club) ran at North Ormesby Youth and Community Centre for 4 weeks in the summer holidays. Parents 4 Change members helped train the staff.

Parents have said:

**“Some of our children are unable to access mainstream activities so the introduction of specialist play schemes has been most welcome, so our children can join and take part in activities like any other child.”**

**“C has enjoyed his time here, a happy boy. He is able to mix and enjoy the activities. Lovely times he has had with great staff”.**

### **Youth Clubs and Activity Groups**

Families wanted:

- **“In my dreams I dreamt about coming to a Youth Club and doing what I want”**
- **“youth club where our son can be safe and comfortable”**
- **“special interest groups in a safe and secure environment”**

Extra work has taken place at Kader Youth Club and North Ormesby Youth Club, both now have:

- A session which runs once a week which is just for children with disabilities
- Experienced staff
- A sensory room

Training has been provided to Youth Workers so Youth Clubs can be more inclusive.

Additional activity groups have run for children with disabilities including:

- An Art and Craft Group
- A girls' group

What families have said:

- **“New services have been introduced – e.g. Kader Youth Club and existing ones improved.”**
- **“Brilliant – makes a big difference – able to spend time with other child while son out.”**

## **Choice and Control**

Some families wanted to continue to use traditional services:

- residential overnight breaks at Gleneagles
- Support in the home and in the community from the South Tees Home Support Service and South Tees Activity Support Service (STARS).

Some families want to have more control and have a Direct Payment or Individualised Budget so that they can organise their own support.

Families want a full range of services to be available so they can choose what is right for them and their children.

### **Kerrie's Experience**

Kerrie opted for a mixture of services that met her families and child's needs. Her son Warren attends Gleneagles and also has a Direct payment, both of which he thoroughly enjoys. This gave him the opportunity to choose what activities he wanted to do.

Both of her boys play disability football for a Centre of Excellence and they have made great progress in this

The opportunity and choice this has given children and their parents has been vast, children have been given the choice and opportunity to try activities they may not have had the chance to do otherwise.

Accessing mainstream activities without support can be difficult for my boys and they gain so much from football. Owen was voted North east Disability player of the year 2010.

Kerrie is so proud of what her boys have achieved, and knows there is another child who is learning to play golf much to the surprise of many people.

Children can achieve so much given the right support and opportunity to do so. Without short breaks funding, these opportunities for children with disabilities will be greatly reduced. Other families have chosen to buy a season ticket for the Boro, sports clubs, youth clubs etc, the choice is vast and that's what parents wanted: 'The Choice'.

### **What has been provided:**

- Traditional services continue to provide short breaks to families and have been able to improve and increase the level of support.
- New ways of working have been piloted including Individualised Budgets and more direct routes to short break services.

### Family Quotes

**“My child is on an individualised budget. He is now able to go to after school clubs, sports club and has bags more confidence. As a family, we can now spend more time as a family, doing normal family things.”**

**“We made the decision to take part in the pilot of the individualised budget because we wanted our package of support to be more flexible.”**

**“Gleneagles provides much needed respite for us as carers. We have no relatives locally and have triplets with special needs. We can only cope if we have this service from Gleneagles. Our sons are happy there and get to do different activities from home. Gleneagles is a lifeline to us and other families and that is partly due to the magic dust raining down constantly on Gleneagles and the wonderful staff.”**

**“It is very important for families to have a break from the daily struggle and stress a family member with a disability causes. The daily struggle and stress have an impact on the physical and mental wellbeing of other family members. Hence, short break services provide families an opportunity to ‘recharge the batteries’. At the same time, relationships between other family members are reinforced by becoming better and closer.”**

### **What Happens Next?**

Parents 4 Change know that the funding from Aiming High was until March 2011 and that there is now a delay in planning until there is information about future budgets.

The Parents 4 Change Steering Group hope that continued funding will be available from April 2011. We need the support of all parents to enable us to continue, improving, influencing and safeguarding services for all our children now and in the future.

**“The negative impact on families if the services were removed, not just for the child who is unable to or struggles to access mainstream services, would be disastrous.”**

**“Parents have tried and are still trying so hard to improve things for their children and their families - if services are taken away then it’s the children who are most vulnerable that will suffer.”**

Quotes from parent/carers at the conference with regards to the value of Middlesbrough’s Short Break programme:

**Without Short Breaks money we just couldn’t go anywhere as a family**

**To some families, they go on holiday to Disneyland and come back raving about it – well to us, our one day out to Flamingoland through the Aiming High Short Breaks funding *is* our Disneyland!**

**My son writes on his Facebook page about the fantastic time he is having on our family day out – just like *all* kids do**

**The trips are the only things that my son goes on, without them I wouldn’t get him out of the house**

**The trips help me to bond with my family and helps my child connect with other kids**

**I just love seeing my son signing with other kids**

## **In Control**

Gerry Kelly

In Control is a national, social enterprise organisation working to implement self directing support/Individualised Budgets for people with disabilities.

They work with over 140 local authorities across the country and Gerry works with Children’s Services within these authorities.

In Control give support to these Local Authorities by running training days, talking at events and holding residential conferences where two delegates from an authority are able to attend and now a third place is being offered to a parent/carer. Gerry therefore extended an invitation for a parent to attend the next conference which is being held in November in Manchester. The conferences give people the chance to talk, share experiences and develop services for the future.

There are a lot of concerns at the present time because of the Spending Review, Green Paper etc but Gerry stressed how this is an opportunity to create real change and for families and organisations to lobby and create a pathway forward to meeting the needs of disabled children, young people and their families.

An evaluation of Individualised Budgets is currently being undertaken in Middlesbrough to collect evidence to strengthen the lobbying to government. A positive to take from the government is that within 48 hours of them coming into power, Individualised Budgets was featured on their executive summary.

Individualised Budgets are not a fad, they are also not just for certain young people with disabilities; they are available to all regardless of age. The key to Individualised Budgets is to build more resilient families; families are the experts and know their children better than anyone so it is vital that they are at the very centre of this.

One of the key benefits of receiving an Individualised Budget is that families feel they can be a central part of their community and society and be seen more as a family unit enjoying an ordinary life.

There has also been a very clear message from families that they cannot go back now, they want to keep this system and make it available for more families to ensure everyone gets an equal share of the support available.

## **Individualised Budgets – A Parent’s Perspective**

Martin Wilson is a local parent whose family has benefited from receiving an individualised Budget as part of the Middlesbrough pilot.

The family have two sons, the eldest of which attends Priory Woods School, has complex needs including no speech and relies on family and school for every aspect of his care.

Receiving an Individualised Budget has been absolutely fantastic and inspirational as it has meant the family could do so many things that they would have been unable to do without it.

Prior to Individualised Budgets, the system was very rigid and out of their control as a family but they now look after the care and decide exactly what care is required which means it is far more flexible and gives the family respite when they need it. It not only benefits the child with a disability but the family as a whole.

The family love to go on holidays together. In ordinary circumstances, they would have had to try and manage without any support which would mean it was never much of a holiday for them. However, with the Individualised Budget, this has meant that the family can use some of the money to pay for a carer to accompany them on holiday. For the first time, they could actually relax, lie on the beach, eat a meal etc knowing that their son was happy and cared for.

Their son has a great relationship with his carer and is also developing new relationships through her and her family which is also of great benefit to him.

The Individualised Budget gives families real flexibility around costs as it can be used to pay for activities such as horse riding, going to see shows or going to a football match. It can fund small things that have a huge positive impact on us as a family.

It is acknowledged that an Individualised Budget may not be suitable for every families but for those that do want to receive them, it means being able to do more as a family unit and we cannot imagine life now without it.

It is therefore vital that more people lobby to keep this system in place.

## **New Development - Cycle Tracks**

A section of the Department of Children Schools and Families Aiming High Good Practice DVD was shown to highlight how funds had been spent in Hull on establishing a cycling scheme for children and young people with disabilities.

Diane Simon, Project Manager of Build Cycle tracks In Middlesbrough then spoke about the plans to replicate a similar scheme at Prissick Cycle Park on Marton Road.

The aims of the project are to encourage people of all abilities to be more active and to support local people to reach their full cycling potential.

Jenny Dalby, Children with Disabilities Team in Middlesbrough, had contacted the project to see how disabled children and young people could have access to this scheme.

Aiming High capital funding has been allocated to fund specialist bikes and trikes to ensure that all children and young people can enjoy the facility.

The project want the cycle park to be a completely inclusive facility and invited parents to help form a small working group to ensure this aim is achieved. This group will help to ensure the right equipment is purchased and also ensure there are no barriers to stop disabled children and young people enjoying themselves at the cycle park, including looking at accessible toilet facilities and providing a changing place if possible.

The following website is available for people to keep up with developments:

<http://www.middlesbrough.gov.uk/ccm/navigation/transport-and-streets/where-can-i-walk-and-cycle/prissick-cycle-park/>

## **Short Break Services Current Financial Position**

Jenny Dalby, Middlesbrough Children with Disabilities Team

### **Background**

The Children Act 1989 placed a duty on Local Authorities to promote the welfare of children in need by providing services to meet their needs.

A child is defined as being in need under the terms of the act if they are disabled.

Following the 1989 Children Act Local Authorities re-examined the way services were provided to Children with Disabilities

- Specialist Social Work teams for children with Disabilities were created
- Better information was provided
- Respite care - now known as short break support - was provided.

During 2007–2008 Middlesbrough Council spent approximately one million pounds on short break services including:

- Gleneagles Resource Centre
- South Tees Home Support Service
- A budget for Direct Payments
- A budget to purchase support from other providers

### **Aiming High for Disabled Children**

#### **Additional Funding**

A specific grant of £280m to deliver a step change in the provision of short breaks for disabled children

The funding for Middlesbrough

#### **February 7th 2008 - Announcement of Funding allocations for Middlesbrough:**

##### **Short breaks:**

2008 – 2009 - £40,000

2009 – 2010 - £217,000

2010 – 2011 - £701,000

##### **Additional funding available for Capital Work**

2008 – 2009 - £0

2009 – 2010 - £109,600

2010 – 2011 - £256,000

## **Capital Funding**

Planned work included:

- Provision of sensory rooms at Kader and North Ormesby
- Improvements to Gleneagles Resource Centre
- Creation of working area at Viewley
- Purchase of equipment – including hoists, bed, training materials
- Purchase of trikes for new cycling centre

Current provision

- Following the change in government we were told to wait for the funding to be confirmed
- We have now been informed that most of it can be spent– we await final confirmation for around £60,000
- We need to spend the money before the end of the year – if it is not spent as agreed it will have to be returned.

## **Short Break Funding**

2010 – 2011 £701,000 has funded:

- Outings and activities
- Summer Playscheme
- Individual Budgets
- Increased Direct Payments
- Grants to organisations to provide short breaks
- Additional support from Gleneagles South Tees Home Support Service and STARS
- Texting and information services

Short Break Funding in Middlesbrough

This Year

There have been three sources of short break funding this year:

- Aiming High Grant  
(£701,000)
- Carers Grant  
(£162,000)
- Middlesbrough Council  
(£1 million)

Next Year

We do not know what will be available next year

- Aiming High Grant - will have ended – we do not yet know whether anything will take its place
- Carers Grant – current allocation will have ended – we do not know if it will continue
- Middlesbrough Council – we do not know what the budget will be for next year - and the Council will not be able to pick up the shortfall if grant funding ends

The future is unclear but:

- A change to legislation means that Local Authorities will have a duty to provide short breaks
- Senior managers are aware of the impact short break services have on families - they are aware of Parents4Change
- A Green Paper on special educational needs and the lives of disabled children is due to be published this autumn.

## What Happens Next?

Kathy Rist – Regional Manager, Contact a Family and Parent Participation Adviser for Together Disabled Children

Aiming High **has** made a difference. We all know that budget reforms will be tough so we need to make sure we all contribute to get our voices and views heard.

Three years ago, parent/carers of disabled children did not have a collective voice; today the Mayor of Middlesbrough has been in attendance at this conference which illustrates how far we have come.

The achievements made so far have been done by parents working collaboratively with the Local Authority and this needs to develop and strengthen to ensure Parents 4 Change continues to be successful in improving the lives of local disabled children and their families in Middlesbrough.

Kathy congratulated all those involved for their commitment and efforts so far and encouraged more parents to join up and get involved.

# **Key working**

Maria Bache, Key-Working

## **An Introduction to the Key Working Pilot Project**

### **What is Key Working?**

- Research over many years has highlighted the need for key working and care coordination for families who can be overwhelmed when their child has a disability and/or health needs
- Parents can come in contact with many different professionals and be overloaded with various issues and information especially in the early stages.
- A Key Worker will support the family and coordinate professionals/care.

Aiming High for Disabled Children's main aim is to give parents/carers a strong voice in the development of services for disabled children. In Middlesbrough this has been progressed through the Parents4Change Conference, Focus Groups and the Key Working Steering Group.

### **What is a Key Worker?**

- Someone who offers support to families who have a child/young person with severe disabilities and/or complex health needs.
- Central point of contact
- They offer practical and emotional support
- They are able to provide information/sign post
- Someone who will work with the whole family and not just the child/young person
- They work with the families strengths and expertise on their child
- Key Workers keep in regular contact the family (not just at times of crisis)
- They act and work on behalf of the family and not the agency they work for
- They are able to organise and run Multi Agency meetings the are Family Focussed and produce a Multi Agency Plan
- Parents can express who they want their worker to be

**Key Workers don't have all the answers!!**

## **Key Working Pilot in Middlesbrough**

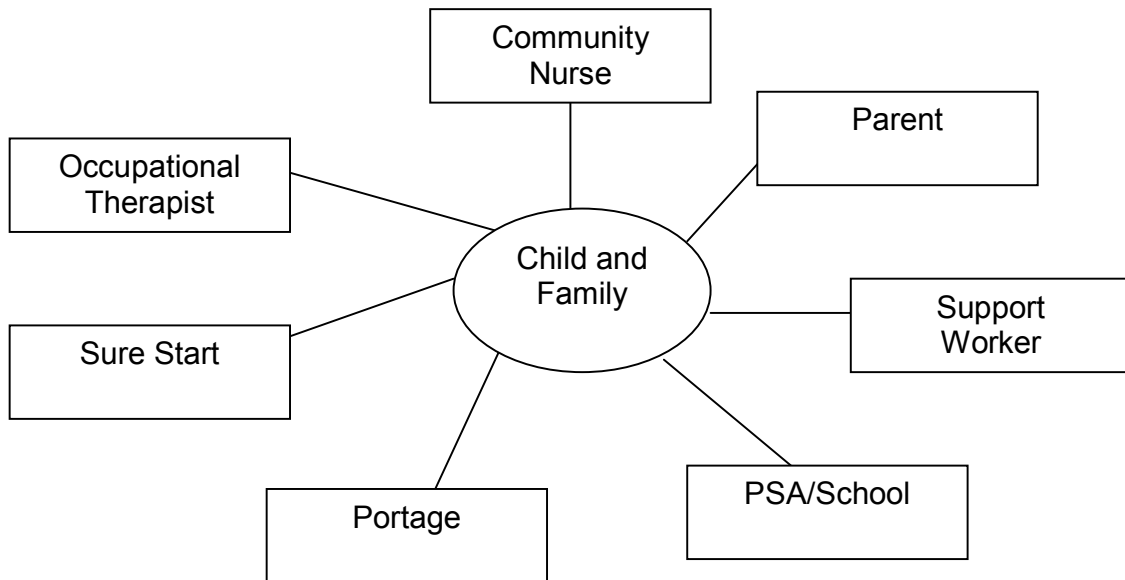
- The aim of the Pilot is to provide families with a more coordinated approach to services
- It is hoped that families will benefit from having a key worker in place, and that Middlesbrough will benefit from the project by learning more about how key working can work in Middlesbrough
- The Middlesbrough Key Working Pilot is in place until December 2011, when the pilot will be evaluated
- The Pilot will work with 40 families who have children with severe disabilities and complex health needs.
- 20 children between the ages of 0 – 5
- 20 children between the ages of 6 - 16
- Families will be identified for the Key Worker Pilot Project through the Children with Disabilities Resource Panel and Cleveland Unit Referral Meeting – to include children referred from neonatal service.
- Families will be asked to give informed consent to the Pilot.

If a family has more than one child with a disability that fall within the two different age groups then the key worker would look at each individual's needs, discuss these with the family and agree with them if they want one person to do a dual role or two different key workers.

## **Who will the Key Workers in Middlesbrough be?**

- There are two types of key workers, those who key work alongside their normal job and those who key work full-time
- Key Workers come from a range of backgrounds professionals/parents/volunteers
- Key Workers will need to have the support and agreement of their line managers.
- Key Workers will have the agreement of agencies to make referrals to apply for services

## Sample of typical Key Workers



## Support for Key Workers

- Monthly Supervision by Key Worker Coordinator
- Support from the Key Worker Coordinator with the first visit /meeting or any other aspects with the key working role
- Peer Support from other key workers
- Buddy System
- Key Worker monthly meetings
- Administrative support
- Key Worker Resource pack

## Training

- One day training day for key workers on the 11th November 2010
- There will be review of the Key Workers training needs taking into account the needs of the child/family
- One day further training and Evaluation May 2011
- Training on key subjects e.g. autism
- One day review and evaluation with families November 2011

## Family Focussed Multi-Agency Meetings

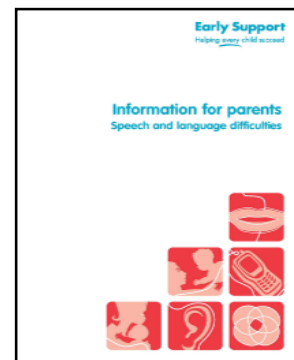
- Keeps families at the heart of decision making about their child
- Prevents professionals working in a “bubble”
- Helps everyone working with a family to review how things are going with joint shared priorities that the family agree with
- Empowers families

## Information for Families

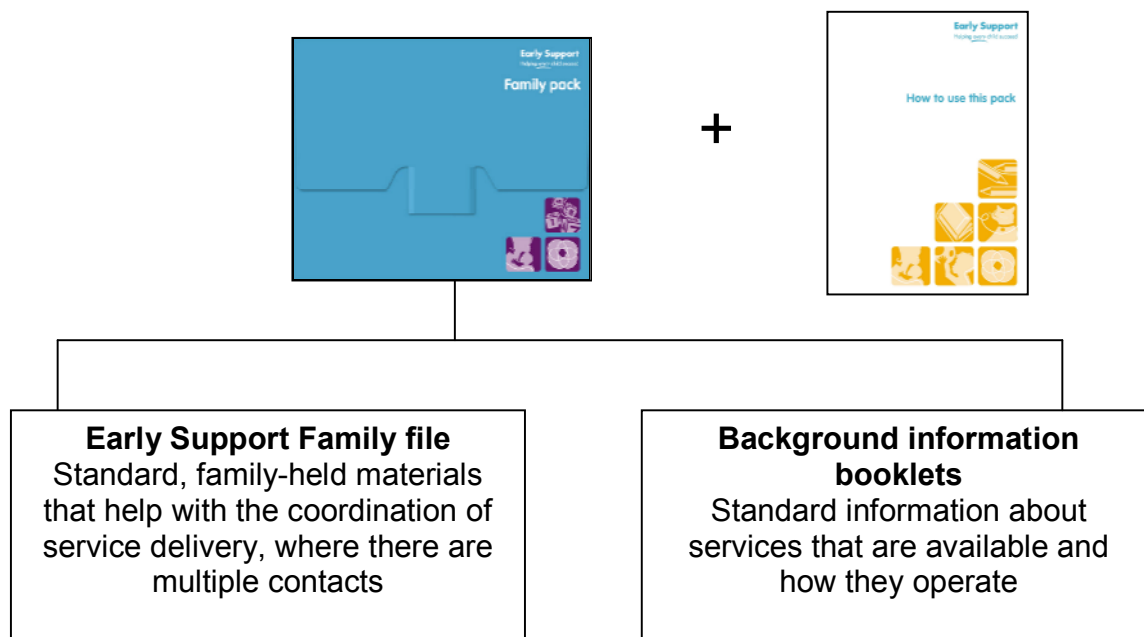
- Early Support Information for parents booklets
- Early Support Family pack (with background information booklets)
- Early Support Professional guidance
- Early Support developmental materials
- Care Coordination Network UK (CCNUK)

## Information Booklets for Parents

- Provide first step information for families beginning to find out about their child’s situation
- Pass on advice and tips from other parents
- Identify sources of information and support that may be particularly relevant
- Were developed in partnership with families who have ‘been there before’.



## Early Support Family Pack



## Family File

- Stops families having to repeat their story to every new person they meet
- Helps professionals find a starting point
- Supports transitions
- A celebration of the child's journey

## Professional Guidance

- Helps to facilitate partnership working with families and drive the development of multi agency service provision at a local level
- Informative chapter on key working
- Offers advice on how to effectively communicate with families when an impairment, condition or disability has been identified.



## Standards and Audit Tool

- The Pilot will work to the Standards set by CCNUK - Care Co-ordination Network UK the National Organisation which promotes Key Working.
- The Pilot will be Audited in line with these standards

## For more information about Key Working in general

- Please visit the Early Support website where you can access information and order materials: [www.earlysupport.org.uk](http://www.earlysupport.org.uk)
- For information on all aspects of key working or Copies of CCNUK's Key Worker Standards go to **Website: [www.ccnuke.org.uk](http://www.ccnuke.org.uk)**

## For more information on Key Working in Middlesbrough

Maria Bache - Key Worker Coordinator  
Norma Rush - Admin

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## **The Junction**

Lawrence McAnelly

The Junction offers a service to Young Carers including support and access to fun activities. By the end of September 2010 they have held 99 sessions and 81 Young Carers have been engaged.

The definition of a carer can be quite complex but they suggest anyone aged 5-18 taking or sharing the caring of another e.g. friend, sibling, parent, grandparent. This can be around Mental Health and Substance Misuse, not just those who are physically disabled. Some young people don't like the label; they just see themselves as young people who care within their ordinary family life.

The Junction supports over 25 families in Middlesbrough, receiving referrals through other agencies as well as self referrals from families themselves. Junction staff will go out and visit a family, complete an assessment and then invite the young carers to groups, activities and one to one support if required.

One issue is the number of Young Carers that there are and the limited resources within The Junction which means they are often not able to offer as many sessions as they would like.

Each Young Carer is treated very much as an individual. They are the ones that receive the invitations to events in the post, not their parent/carer.

Young Carers within The Junction are currently working on an information pack and they have already collectively designed a logo to use.

A number of presentation slides were then shown, each of which had been produced by a Young Carer who attends The Junction and her words sum up best the benefits the service can offer.

**“The Junction is a really good place to be when you need a break from thing's what are bothering you at home. You can talk to the staff about any think that's bothering you or you just have a normal chat they are here to talk and listen to what ever you have got to say”**

**“We go to lots on different places like the beach, the football stadium, bowling and we have been mini monsters. The reason we go on these trips is to get a break from the people we care for. On these trips we also get to spend time with children who know what you are talking about in stead of people just nodding there heads and saying i understand when really they don't. You will never know what we go throw in till you do it your self”**

**“At the Junction you make really good friends and with some people they become best friends for life and every time they see each others you hug and you don’t leave each others sides. You become family at the Junction. At the Junction you get lots of support from the people what are around you”**

**“Do you want to know about the Junction? Well here goes. The Junction is all about helping young carers have a break or if they need to get something off there chest. They help you get through bad times and if your angry they help you calm down a lot”**

**“The junction does a lot of things to help you and they support you on every step you take!”**

Contact Details

**The Junction**

19 Station Road

Redcar TS10 1AN

01642 756000

[info@thejunctionredcar.com](mailto:info@thejunctionredcar.com)

## **Sports & Leisure**

(Bernard Harland was taken ill so in his place, Ruth Johnson and Bruce Lowther gave parents information about some of the leisure opportunities available to families)

- Kader Youth Club held on Saturdays
- Ormesby Table Tennis club – 3 specific times for children with disabilities
- Southlands Friday night club
- Girls’ Group

## **Disabled Children's Access to Childcare (DCATCH)**

Jacqui Callaghan, Service Manager, Prevention

### **What is DCATCH?**

- Middlesbrough has been allocated grant funding to assist parents of disabled children to arrange childcare, if they wish to start work or undertake training.
- This can also include working parents or parents who are studying but wish to change or extend their hours, and will need childcare to do so.
- The funding is called DCATCH and is available until March 2011.
- It is specifically intended to help overcome the potential barrier of higher costs to secure childcare, and support parents who want to start work or training

### **Why Parents May Need Extra Support**

- Childcare can have many forms and parents make a multitude of arrangements between family, friends, schools and carers, to meet their child's needs. DCATCH support is for Ofsted registered settings such as: childminders, before and after-school clubs, holiday care and day nurseries.
- All parents and carers pay for childcare but parents and carers of a child with a disability may find that childcare is more difficult to arrange.
- It may be more expensive because the child needs a higher level of support or a longer period to settle than other children the same age do, or because the provider requires some additional equipment or training.

If a service is approached by a family and then identify the fact that they can't provide childcare because of a lack of suitable equipment or because they don't open on a particular day etc then providers can approach the FIS for help.

A panel then meets to discuss these needs and parents from the Parents 4 Change process were asked if they would like to be involved to help make these decisions. The next panel meeting is being held on 1<sup>st</sup> December 2010.

### **How do parents apply?**

- Application forms are available from the Family Information Service.
- The Assisted Childcare Panel will review applications and aim to have an answer on the level of support available for you, within 2 weeks.
- Requests for funding are supported by a Common Assessment Form (CAF). This is a universal, holistic assessment for all children, and will give the Assisted Childcare Panel a wider understanding of your families' circumstances to enable them to offer the right guidance and support.
- Staff at FIS will be able to help you complete the CAF.

## **Family Service Directory**

[www.middlesbrough.gov.uk/fsd](http://www.middlesbrough.gov.uk/fsd)

- An online directory of services.
- The website covers information on services and activities for children, young people, parents, carers and practitioners in Middlesbrough.
- This is a national Government database
- Local information from the Family service Directory is uploaded to the FID
- The FID is the source of information and this feeds the directgov website.

## **How to Contact the Families Information Service**

- Located within Middlesbrough Bus Station, Unit 10, opposite the florist, off Captain Cook Square.
- Telephone: 01642 354200  
Opening Hours for Telephone Service: Mon-Thurs 8.30am – 5pm and Fri 8.30am - 4.30pm  
Opening Hours for drop in: Mon-Thurs 9.00am – 4.30pm, Fri 9.30am – 4pm

## **Evening Session**

An evening session was arranged for those parents who work or who are unable to attend the day time conference.

The small, more informal session was chaired by Christine Humphreys-Middleton, Parent member of the Parents 4 Change steering group. The session included re-caps of the morning agenda so that parents received all the information that those in the morning had received.

## **Parent Views gathered during this session**

### **Information Sharing**

- Suggestions for text alert service – include postcodes when giving venue addresses to make it easier to get to places.

### **Short Breaks**

- They benefit us as a whole family
- We get to socialise with our children
- Our stress levels reduce because we can see our children enjoying themselves

## **Sports and Leisure**

- At a previous Focus Group meeting, the issue of signing in all leisure centres was to be addressed, has it?

## **Summary**

From the evaluation comments made by those parents who attended the fifth Parents 4 Change, it is evident that everyone enjoys coming together to meet other parents, learn about new initiatives and services available to them and share experiences. As one parent very simply said:

### **You get to know things if you turn up**

The benefits of working collaboratively with the Local Authority were also highlighted:

### **Partnership working in Middlesbrough has achieved a relaxed open consultation forum that is developing friendships between service providers and service users**

Although we are faced with an uncertain future, many parents remain optimistic because of the work that has already been undertaken and the achievements made so far:

### **Looking forward to a brighter and better future for us and our children**

It is therefore vital that the momentum is not lost and that parents and professionals continue to work together to help to improve the lives of disabled children and their families further.

A full list of evaluation comments is attached as Appendix One.

## **Appendix One – Full List of Evaluation Comments**

### **Something I've learnt from today**

- That there is lot of help and information available
- What is available for children with disabilities
- Cycle Track
- A range of different support groups for my child; help and support that is out there
- Bike scheme at Prissick
- Ray Mallon is mint and on our side
- That there is a lot of support and help out there and how to access it
- All the different agencies and the parent's perspective on budgets, the junction etc
- The number of agencies
- Junction Young Carers Group – much needed help
- How productive parents have been; learnt about what has been going on, especially the cycling track
- About the cycle track at Prissick that I didn't know about before today
- You get to know things if you turn up
- That there are people who care
- When my son was diagnosed with Autism there was no support from any organisations and these places will close if the do not get the funding
- Everyone's in the same boat
- There is help and support out there
- A lot of interesting information but not many telephone numbers to contact these groups/services
- There will be a new cycle track for people with special needs
- New cycle track, disabled bike park; green paper and new budgets and how this year's budget was spent
- The conferences and the consistency of approach to "opening discussions" relevant to parent/carers roles and responsibilities has proved once again to be of great informative value to all involved
- About regional meetings and bike track at Prissick

### **Something I've felt/experienced today**

- Empathy with people on DVDs
- That partnership working in Middlesbrough has achieved a relaxed open consultation forum that is developing friendships between service providers and service users
- How individualised budgets affect/benefit families
- Seeing people enjoy themselves on the bikes

- I felt really comfortable listening to the professionals giving us help and support
- I have found something that we can do as a family
- Friendly advice
- Being anonymous; being a parent not a professional
- I feel that things are starting to change for the better in Middlesbrough for disabled children and their families and this wouldn't have happened without Parents 4 Change
- Common focus and passion from parents and speakers
- Moved by the bike DVD; much needed in Middlesbrough
- A general understanding of the different groups
- It was really positive; well organised with a variety of speakers
- There are lots of people with children and young people who have experienced situations like ourselves
- Being part of the change
- Personal stories
- The Government's intentions of taking away funding that help our children living in the community
- Respect for what Parents 4 Change do

### **Something I'll take away from today**

- Cycling project and text messaging service
- Awareness and knowledge
- Table Tennis club may be useful
- Understanding, help and support
- Enthusiasm of everyone
- Cycling thing, mints, pencils and prize
- Information on how to get the help and support we need and how we can have our say and input
- Key working and information on services for families
- Something to ponder on; the amount of people who are involved
- Other parent's comments about their lives and how they are coping
- Everything – my bag is physically and emotionally full
- Looking forward to a brighter and better future for us and our children
- Information
- Lots of useful information
- Knowing something is being done and we can help
- Knowing there is help
- Information about individualised budgets

### **Something that was not so good about today**

- Long speech – last of all speaker
- Time – there is never enough time
- DCATCH went on for too long, the lady just went over and over the same topics
- No presentation from Speech and Language Therapy. DCATCH was boring
- Some laborious speeches but most informative
- Given in one hand and maybe soon taken away
- All groups are aimed at children with learning difficulties and nothing in Middlesbrough for teenagers confined to a wheelchair who can't use their arms but want to do things that other children their age do as he has no learning difficulties, just physical
- Problems with the equipment; microphone and powerpoint
- All good, food fab (salmon)
- Nothing, it was great
- Not enough time for everything